

BEYOND THE PROGRAM: COMMUNICATION IN NEWBORN SCREENING

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DISCUSSION

Newborn screening (NBS) in Washington State is a collaborative effort between the State Department of Health NBS Program, hospital birthing providers, primary and specialty care providers, the State Board of Health, affected families, and the general public. NBS programs typically provide consultation and technical assistance to inform constituents of testing policies and to promote proper procedures.

This presentation displays a variety of materials developed and distributed by the Washington State NBS Program. These different approaches are intended to coordinate information and enhance understanding to ultimately improve the effectiveness of screening. This has been especially important in light of the significant changes in the American health care system that has impacted NBS practices and long-term care for affected children (i.e., early discharge, managed care).

OBSERVATIONS

A measurable benefit of these communication efforts has been the response to our advocacy for routine second newborn screens. The rate of second screens has increased from 79% in 1990 to 89% in 1994.

In addition to these communications, the Washington State NBS Program produces articles for state, regional and national publications. Program staff also participate in educational forums to provide information to groups interested in issues related to the screening program.

Each communication is produced with a primary target audience in mind. However, there is overlap in distribution. Eight vehicles of communication currently produced are presented in the following table:

| PUBLICATION | PRIMARY TARGET | FREQUENCY | CURRENT DISTRIBUTION | FIRST PUBLISHED |
|-------------------------------------------------------------------------------------------------------------------------------------|-----------------------|------------|----------------------|-----------------|
| Parent Pamphlet: General information about screening & disorders detected | Parents | Continuous | ~140,000/year | 1976 |
| Board of Health Report: Summary of the outcome of screening including costs | State Board of Health | Annual | ~50/year | 1991 |
| NBS Bulletin: Articles & information of current & general interest | Health Care Providers | Annual | ~1,500/year | 1992 |
| NBS Homepage: General information describing program & components & current news | General Public | Continuous | not applicable | 1996 |
| CH Parent Newsletter: Articles & information of interest to families affected with congenital hypothyroidism (CH) | Affected Families | Annual | ~400/year | 1992 |
| CAH Parent Newsletter: Articles & information of interest to families affected with congenital adrenal hyperplasia (CAH) | Affected Families | Annual | ~150/year | 1994 |
| Hospital Compliance Report: Summary of each hospital's summary of number of births & % screened within required timelines | Hospitals | Annual | ~160/year | 1984 |
| Quality Assurance Report: Each hospital's summary of adequacy of completing required data fields on specimen cards | Hospitals | Quarterly | ~240/quarter | 1990 |

Although producing these publications is a strain on personnel resources and a challenge to maintain momentum, we believe the benefits are worth the effort.